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Nicole Caron

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Evaluating Health-Related Quality of Life for People with Multiple Sclerosis:  
A Quality Improvement Project to Promote Peer Support

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### Abstract

**Background:** Multiple sclerosis (MS) is an autoimmune disease that impacts the central nervous system, resulting in symptoms of fatigue, numbness, tingling, weakness, dizziness, pain, spasticity, gait disturbance, and depression. How individuals cope with MS may shape adjustment, impacting health outcomes both physically and psychologically. The difficulties that MS may present can result in patients experiencing depression and decreased quality of life. Peer support has been shown to help reduce problematic health behaviors and depression, and to improve medication behavior adherence. While peer support is known to be beneficial in many types of chronic illness, it is unclear whether peer support is beneficial for people with MS.

**Purpose:** The purpose of this DNP project was to execute peer support interventions to evaluate how peer support may impact health-related quality of life (HRQOL) in people living with MS.

**Methods:** Peer support groups were held once a week for six weeks for participants who are living with MS. Participants completed questionnaires before the first peer support group, and then at 3, 6, and 9-weeks, using quality of life as an outcome measure to evaluate the effectiveness of this peer support program. **Results:** Health-related quality of life was not consistent in participants during the peer support sessions. **Conclusion:** People with MS have symptoms and circumstances that vary on a daily basis, and this can impact their health-related quality of life.

*Keywords:* peer support, multiple sclerosis, health-related quality of life

## Evaluating Health-Related Quality of Life for People with Multiple Sclerosis (MS): A Quality Improvement Project to Promote Peer Support

Multiple sclerosis (MS) is an autoimmune disease that impacts the central nervous system, resulting in symptoms of fatigue, numbness, tingling, weakness, dizziness, pain, spasticity, gait disturbance, and depression (NMSS, 2015). Ultimately, MS can impact the day-to-day lifestyles of people who live with it, affecting “body functions, daily life activities, and participation and environmental factors” (Salminen, Kanelisto, & Karhula, 2014, p. 1983). People living with MS can suffer from uncertainty of their illness, and how individuals cope with MS may shape adjustment, impacting health outcomes both physically and psychologically (Roubinov, Turner, & Williams, 2015). Individuals living with MS can go through unpredictable relapses and progression of the illness, which can cause people with MS to be uncertain about their future daily functioning (Wilkinson & das Nair, 2013). The difficulties that MS may present can result in patients experiencing depression and decreased quality of life. Peer support may help to improve these difficulties.

Peer support is the giving and receiving of “informational, emotional and appraisal support” between individuals who share a common health condition (Dennis, 2003, p. 6). Peer support has been shown to help reduce problematic health behaviors and depression, and to improve medication behavior adherence (Heisler, 2007). Peer support is especially useful in chronic illnesses because these are illnesses that will not go away. It is important that people can manage the physical and psychological effects of these illnesses. Despite the amount of research that has been done in chronic illnesses such as diabetes, the evidence of peer support for MS is lacking.

Since MS can affect many body systems, including physical ability, memory, and cognition, many patients with MS benefit from support from their peers, and report an improved health-related quality of life with support (Salminen, Kanelisto, & Karhula, 2014).

Unfortunately, the evidence in the literature is outdated and is lacking regarding peer support in this population of patients.

### **Problem Statement**

Multiple sclerosis can lead to physiological deficits that result in emotional distress, reduced quality of life, alterations in physical functioning, and loss of control over life circumstances, and without peer support, can also result in feelings of loneliness and isolation. It is important to evaluate the implications that peer support can have on individuals who live with MS, and whether this will improve health-related quality of life. By providing a peer support group to people living with MS, more information can be obtained on whether this approach will be helpful in improving health-related quality of life in this population.

### **Review of Literature**

#### **Methods**

A comprehensive search of the literature for evidence of peer support in diabetes and in multiple sclerosis included the following databases: Cumulative Index of Nursing and Allied Health Literature (CINAHL) and PubMed. The following Medical Subject Headings (MeSH) terms were used for the CINAHL and PubMed searches: *peer support and diabetes*; and *peer support and multiple sclerosis*. The PubMed search was also limited to randomized controlled trials (RCTs). One hundred fifteen articles were retrieved from the search of the above databases using the selective search MeSH terms. Inclusion criteria consisted of full-text articles published in English. Studies were identified from 2000-2015 for multiple sclerosis due to lack of articles,

and from 2010-2015 for diabetes. Of these, one was expert opinion regarding a previous RCT study, numerous studies did not include peer support of people with chronic illnesses interacting with other people with that chronic illness, one study was a design that has not been carried out, and eleven studies did not apply to the search topics. In summary, of 115 articles, 106 had to be eliminated, leaving nine studies that were relevant to this review. Discussion of studies follows herein.

## **Results**

The selected nine studies resulted in one meta-analysis, three randomized controlled trials (RCTs), two prospective cohort studies, one literature review, and two comparative studies. All of the articles involved people with multiple sclerosis or diabetes interacting with other people with the same illness and evaluating if this interaction affects certain aspects of their health.

## **Discussion**

**Peer Support in Diabetes.** Examining literature focused on diabetes provides current examples of research on peer support in this chronic illness. Diabetes treatment requires daily self-management in order to prevent complications (American Diabetes Association, 2016). This responsibility can cause psychological burden and stress, and can cause a feeling of isolation from other individuals. People with diabetes oftentimes turn to others with diabetes for peer support. Improving diet, increasing exercise, monitoring blood glucose and adhering to medications are self-management strategies that can improve with peer support (Qi et al., 2015). Qi et al. (2015) used a meta-analysis of RCTs to evaluate the effect of peer support in glycemic control in type 2 diabetes. It was found that with peer support there was a 0.57% reduction in HbA1c levels. Yin et al. (2015) performed a study in which patients with fair glycemic control went through training on diabetes management. The control group did not go through the



training. The patients who went through the training and provided peer support had better self-care improvements, and also maintained better glycemic control. In an online support group, users reported that their peers with diabetes offered different support than clinicians could, including social and emotional support. Online users reported gaining encouragement, motivation, self-reflection, and a sense of community, which positively helped them manage their diabetes (Gilbert, Dodson, Gill, & McKenzie, 2012). Another study examined 127 participants with diabetes to evaluate peer education and the effects on patients with type 2 diabetes and emotional disorders. The results of the study indicated that peer education can improve self-management, mood, and quality of life in these individuals (Liu et al., 2015). The similar theme in these articles is that peer support helped to improve health results in diabetic patients, physically, psychologically, and emotionally.

**Peer Support in Multiple Sclerosis.** Multiple sclerosis is a demyelinating illness of the central nervous system, affecting more than 2.3 million people (NMSS, 2015). MS can be divided into two classifications: relapsing remitting MS (RRMS) or progressive MS. RRMS is defined as having periods of exacerbations and periods of remission, whereas progressive MS is when exacerbations can progress (NMSS, 2015). Regardless of the classification, people with MS can suffer from uncertainty in their illness. How individuals cope with MS may shape adjustment, impacting health outcomes both physically and psychologically (Roubinov, Turner, & Williams, 2015).

Limited studies examined the effect of interventions on people who have multiple sclerosis and interacted with other people who have multiple sclerosis. One study analyzed how individuals with MS perceive MS-related meetings (Peters, Somerset, Campbell, & Sharp, 2003). Three hundred eighteen people responded to questionnaires after attending a meeting, and

approximately half of these people found the meeting helpful. Embrey (2009) conducted a study to explore the opinion of people with MS at a hospice facility that participated in a palliative day program. The participants reported positive experiences psychologically, physically, and socially. Rigby (2008) evaluated mood, self-efficacy, and resiliency after a group psychological intervention involving patients with MS, and found that there were benefits from psychosocial intervention and psychological intervention together. Ng et al. (2013) conducted a pilot study that evaluated how peer support programs can improve quality of life in people with MS, focusing on multiple sclerosis-related depression, anxiety and stress. At the 6-week assessment, participants reported improved psychological functioning and quality of life, and were less likely to use self-blame. At the 12-week assessment, participants still had positive improvements in stress and quality of life (Ng et al., 2013). These studies examined improving quality of life by using peer support in individuals living with multiple sclerosis, however there have been few studies that solely examine how support groups for people with multiple sclerosis may or may not improve quality of life.

### **Gaps in Research**

The above studies utilized group methods in trying to improve quality of life in people who live with diabetes or multiple sclerosis, by allowing these individuals to interact with other individuals living with diabetes or multiple sclerosis. In all of the studies, people with these illnesses who interacted with other people who have the same illness reported improved quality of life, improved health, or improved coping methods. The studies related because participants reported liking interacting with other people with the same illness, and this helped them cope. There are many more articles examining peer support in diabetes than peer support in multiple sclerosis, so gaps in research exist regarding peer support in multiple sclerosis. The studies for

MS all demonstrated benefits from peer support in MS, however there is a lack of evidence and consistency available for this subject. A number of the articles available discuss peer support led by nurses, doctors, communities, and schools, however not peer support from others living with multiple sclerosis. Other studies are pilot studies, and have not been carried out long enough to provide substantial evidence that peer support groups are beneficial for this population of patients. Additionally, the studies that are available do not consider peer support through different age groups, leaving a huge gap in the research. Finally, there are multiple studies that are designed, but that have not been carried out.

### **Theoretical Framework**

Nola Pender's Health Promotion Model (see Appendix A) describes the multidimensional stages people go through as they interact with their surroundings to improve their health. By promoting health behaviors in interpersonal and physical environments, a person should have better health outcomes and improve their quality of life. The Health Promotion Model is influenced by individual experiences and by behavioral outcomes from experiences (Alkhalaileh, Khaled, Baker, & Bond, 2011). Peer support interventions are used in multiple settings to target physical health concerns (Simoni, Franks, Lehavot, & Yard, 2011). The Health Promotion Model helped guide this DNP project, in which individuals with MS interacted to discuss their experiences, and formed relationships with others who understood what symptoms they had been through. De Vries et al. (2014) state that interventions for peer support oftentimes include emotional, informational, and appraisal support. The four main functions of peer support are helping to use skills to manage illness in day-to-day life, providing emotional and social support, encouraging individuals to go to their doctor when needed, and providing unlimited support (Gilbert, Dodson, Gill, & McKenzie, 2012).

During peer support interventions, patients with an illness can provide support to other patients with the same illness. This provides an outlet for patients to provide support and in turn they may also receive support themselves. Evidence shows that providing peer support to people with the same illness can also result in health benefits comparable to receiving support (De Vries et al., 2014). People who provide social support have beneficial outcomes, such as less depression, improved self-sufficiency and morale, improved quality of life, improved health-related behaviors, and decreased risk of mortality (De Vries et al., 2014). This quality improvement project will be guided by the Health Promotion Model and will use peer support in individuals with multiple sclerosis to determine the efficacy of providing and receiving peer support for these individuals and how this influences their health-related quality of life.

### **Project Design and Methods**

This DNP Project was organized using Plan-Do-Study-Act (PDSA) Method (see Appendix B). The PDSA method uses a plan to test the change (plan), carries out the test (do), observes and learns from the consequences (study), and determines what modifications should be made (act) (Institute for Healthcare Improvement, 2016). Utilizing this model allowed for changes to be made after responses from the study stage and before the act stage, based on the analysis, in order to receive the best results (HRSA, 2016).

Quantitative and qualitative methods were used, including a pre-test self-reported questionnaire, follow-up self-reported questionnaires during the support groups, and a post-test self-reported questionnaire to evaluate the group peer support meetings. The main purpose of this project was to evaluate how a peer support group may improve MS-related distress and therefore health-related quality of life.

The quality improvement project consisted of six sessions of peer support intervention in a group setting led by the DNP student and attended by the program coordinator for the MS Society at the Waltham office. The DNP student has multiple sclerosis and the MS coordinator has extensive background about MS. The MS coordinator helped support the peer leader when questions arose that needed clarification. The primary outcome measure was quality of life in people living with MS (see Appendix D for scoring quality of life). Participants continued with their routine treatment plan.

### **Project Site and Sample**

The DNP Project took place at the MS Society in the conference room in the office. Participants took part in one-hour peer support sessions once a week for six weeks. The peer leader discussed topics related to multiple sclerosis, such as depression, fatigue, medication adherence, communication with providers, and any concerns (De Vries et al., 2014). The goal of these sessions was to encourage interaction and to provide education to topics of interest to help promote self-efficacy to allow participants to cope better with multiple sclerosis. Communication between participants allowed informational and emotional support to take place.

The purpose of the DNP project was to implement peer support between people living with MS and to evaluate quality of life in participants to see if it helped improve their quality of life. It was hypothesized that participation in the peer support group would decrease MS-related distress leading to an improvement in health-related quality of life.

**Description of the group, population, or community.** The population consisted of English-speaking adults over the age of 18 from the community who have been diagnosed with MS (see Appendix E for participant demographics). The participants were also from a limited geographic area, as this was where the support groups were held. Participants had the

opportunity to build relationships so that they may eventually provide support to each other in the future.

**Organizational analysis of the project site.** The National MS Society chapter involved in this project specializes in multiple sclerosis, raises funds for research, advocates for people living with MS, facilitates professional education, and provides support services to help people living with MS. This organization offers many services, including counseling, peer facilitated support groups, educational programs, referrals to neurologists, and recreational programs to help people with MS and their families lead productive and fulfilling lives. There is limited data on peer support groups related to multiple sclerosis, so this project aimed to provide information to close the gap on peer support in this population of patients. There is a president and vice president of the chapter who helped facilitate this DNP project, as well as the program coordinator and program manager for case management who helped recruit participants and who sat in the peer support sessions to answer questions and offer guidance when needed to participants.

**Facilitators and Barriers.** Evidence from the literature is limited on the effect of peer support and multiple sclerosis. This project provided important information regarding whether using peer support in people with multiple sclerosis is effective in improving health related quality of life, and whether this should be used in the future for this group of patients.

Facilitators to this project were that it was led by a person who is living with MS and by a program coordinator who works in the MS field, therefore they had a knowledge in what the support group was discussing and could provide support to the participants. There was free, handicap-accessible parking with elevators to get to the meeting place. Other facilitators to the project were that the participants had a shared identity in that they all have MS. Finally, the peer

support groups were small, allowing participants to discuss and listen to one another. Barriers to this project were that meetings were held one day per week, so meeting times were difficult for some participants over a 6-week time span. Another barrier was that it snowed on some of the dates of the meetings, so not all participants could attend every session. Participants were in different stages of their MS, with some already coping skills related to disease management, some dealing with relapsing-remitting type MS, some being in the progressive form, and some who had not developed coping skills at all yet in their illness, making some participants having different needs to discuss than others. The participants had variable symptoms from their multiple sclerosis. The participants were also from a limited geographic area, as this was where the support groups were held.

The DNP project was limited because the design depended on the education of the DNP student and the program coordinator and program manager for case management. Another limitation was that the sample was self-selected, and this could be a threat to external validity. Finally, the participants who mainly attended the sessions had already developed strong coping mechanisms and had found a way to be happy with their lifestyle, which may mean that they felt like they already had a full quality of life.

To conclude, this quality improvement project was planned using the PDSA methods for QI projects to examine how a peer support program, led by a DNP student diagnosed with MS and a program coordinator/program manager from the MS society, may impact MS-related distress, well-being and health-related quality of life, and examined how social support affects patients with MS. The results will aim to advance our understanding of the interaction between peer support and MS.

### **Implementation**

## **Recruitment**

Participants were recruited with the help of the vice president of a National MS Society chapter as well as the program coordinator of that same NMSS chapter. They sent emails about this DNP Project to individuals living with MS in the area and provided contact information. The DNP student received emails and phone calls from people who were interested in participating, provided them with details, and accepted any person who was interested into the support group who was at least 18 years of age with a diagnosis of multiple sclerosis who could make a meeting time on Wednesday mornings.

## **Description of Peer Support Programs**

The peer support programs were led by the DNP student, as well as the program coordinator from the NMSS who works with patients that have MS. This allowed participants to relate to the peer support group leaders. The leaders guided the peer support group and had a list of topics to discuss. Participants were also able to guide the discussion. Participants completed surveys regarding their experiences before the week 1 session, after the weeks 3 and 6 sessions, and at the week-9 mark (see Appendices C and D).

The peer support programs took place one day per week for one and a half hours per session. Participants and peer support leaders sat in a circle to promote more conversation between everyone. The DNP student did research each week and created a PowerPoint with certain topics to discuss, as well as questions for the group to answer. The first meeting consisted of a brief explanation of the DNP project, followed by participants completing the questionnaire. After that, there was a team building activity, to build group cohesiveness.

The second meeting discussed resilience, and participants answered questions such as ‘Do you consider yourself resilient?’, ‘Do you think you were always resilient, or was this



something that you had to develop?’, and ‘What was the defining moment for you, where you had to draw upon your resilience, or develop it?’.

In week 3, the peer support group answered questions related to the effect of MS on other activities: ‘What do you do to keep MS in its place– so life doesn’t become all about MS?’, ‘Does making changes feel like you are giving in to the disease or taking charge of it?’, and ‘How has MS affected your ability to participate in the activities you enjoy? Have you found ways to adapt to those activities so that you can still participate or have you found new activities to enjoy?’. The participants were emailed the questionnaire after this session, so that we could have more time to spend talking during the session.

In week 4, the discussion was focused on the story of a woman who was a singer and songwriter who was diagnosed with MS, and how she overcame and coped with her diagnosis. We then discussed: ‘Has MS affected your dreams? How did you overcome that?’, ‘How have symptoms affected your life since an MS diagnosis?’, ‘Does MS impact your relationships with friends, children, spouses? If so, how?’, and ‘What are some examples of when you compensate for MS symptoms?’.

In week 5, each participant defined happiness then discussed whether success fuels happiness, or whether happiness fuels success. This led to a discussion on how to make changes that will positively impact our lives. Further discussion focused on social support, because some participants noted that when they feel like they need someone the most, they tend to isolate themselves. To help create a conversation, open-ended questions were used such as ‘How can you use your strengths to change your perceptions and get things done?’ and ‘How do you plan to share what you learned today with others in your circle of support?’.

In week 6, the discussion topic was health and wellness, including nutrition, exercise, and holistic practices that participants use. We discussed coping, stress, and loved ones. After this session, participants were emailed the questionnaire to complete.

During each session, the questions oftentimes led into other topics of conversation related to MS that participants wanted to discuss. Aside from the questionnaires, there were no handouts during the meetings. The program coordinator was able to answer more specific questions related to the MS society when participants had questions.

### **Ethics and Human Subjects Protection**

The DNP student submitted the IRB determination form to the UMASS IRB. The Human Research Protection Office evaluated the DNP quality improvement project proposal and deemed that it is not considered research under the human subject regulations and therefore does not require IRB review and approval. The DNP student and program coordinator who conducted this project followed the *Standards of Care* for practice by adhering to ethical principles in order to protect the dignity and rights of research participants. All information collected was from the project participants and excluded any potential patient identifiers. The risk to participants in this project was no different from the risks of patients receiving standard care. Participant confidentiality was assured by keeping questionnaires anonymous.

### **Results**

This DNP project consisted of six sessions of weekly peer support groups for people with MS, meeting for 1.5 hours each week. The sessions were led by a person who has MS, and were accompanied by the program coordinator of the NMSS Waltham Chapter. Over the course of this initiative, participants completed surveys before week one, after weeks three and six, and at the nine-week mark to evaluate their health-related quality of life. See Appendix E for demographics

of participants. A scoring system was used to provide ordinal values for responses within the survey (see Appendix D and E). Some of the questions were found from the National MS Society Website from their Multiple Sclerosis Quality of Life-54 (MSQOL-54) survey, while others were created based on this specific peer support intervention (National MS Society, 2016). This DNP project used a scoring system similar to the MSQOL-54, however there were less questions involved and less symptoms of MS addressed in this DNP project, so the scoring was altered (see Appendix D). The positive answers were given higher scores than the negative answers. The independent variable used in the analysis is the number of sessions attended per participant, and the dependent variable is quality of life, though many of the survey questions were also dependent variables.

Initially, there were a total of 10 participants, however one participant dropped out after the first session, and two participants only attended one peer support session, so their data were excluded. One participant did not respond to the week-9 questionnaire, but her other data over the course of the peer support sessions was included. A total of seven participants' data was included, and these participants were present at a majority of the sessions. Consistency was also noted, as multiple questions within the survey were asking similar concepts.

There were three types of analyses that were done with the questionnaire responses. First, the DNP student compiled all of the participant data into one spreadsheet. This included demographics, sessions attended, and all of the questionnaire responses. After that was done, each question was converted to an ordinal scoring system.

The first analysis was looking at consistency of reporting on similar questions by session week by individual participant using graphs (see Appendix F). The categories of similar questions were as follows:

- Category 1 (Q0)= I think my health is going to get worse, I expect my health to get worse
- Category 2 (Q1)= I get sick easier than other people, I am as healthy as everyone I know, I think my health is going to get worse, I expect my health to get worse, My health is excellent, I get sick easier than most people
- Category 3 (Q2)= How often are you discouraged by your health problems?, How often are you frustrated about your health?, How often are you worried about your health?, How often are you weighed down about your health condition?

The first analysis also noted quality of life changes over the sessions (See Appendix F). The results for the first analysis were scattered between questions per participant, with some questions showing consistency throughout the sessions, but with other similar questions not being consistent throughout the sessions. Quality of life also was not consistent on a weekly basis for participants. Due to these inconsistencies, another analysis was done on correlation data between the answers.

The next analysis consisted of using a non-parametric correlation coefficient, Spearman's coefficient. By taking a delta of a later week survey value from the original baseline, the change in the values between the sessions could be evaluated. For example, subtracting week 3 data from the baseline (week 1), and doing the same for weeks 6 and 9 provided a delta. Based on this analysis, the correlation was weak between the quality of life week 3 delta, quality of life week 6 delta, and the quality of life week 9 delta. Quality of life had some weak correlations with 'EverydayLife', 'SickEasierThanOthers', 'HealthIsGreat', and 'LifeAsWhole'. A strong correlation would be at least 0.8, which was found with "EverydayLife" and number of sessions attended. This means that there was a correlation between 'MS affects my everyday life' and the number of sessions attended per participant. Due to the primarily weak correlations, there was no

further indication to do a regression analysis since the results did not strongly correlate. It can be noted that questions are dependent upon number of sessions attended, and not every participant was at every session, so this was also incorporated into this analysis.

The final analysis was to see if by combining similar questions, there would be a reinforcement of the deltas to show stronger correlations. This did not show reinforcement of the deltas or show stronger correlation between these questions, meaning that participants did not answer these similar questions consistently.

Based on these analyses, it is clear that people living with MS may have different feelings on a daily or weekly basis depending on what they are experiencing in their lives. Their qualities of life may wax and wane based on their symptoms, and also their life experiences.

Unfortunately, the data were inconclusive because there was a small sample size and not every participant attended every session. Additionally, the sessions were only 1.5 hours per week, which is a small amount of participants' awake time for the week.

### **Strengths and Limitations**

Strengths of this DNP project were that this was a meeting in which participants could meet other people who were going through similar difficulties as themselves. There was open communication between participants, and freedom to discuss any barriers related to MS that participants wished to discuss. This allowed meetings to cover many topics, and promote encouragement and advice between participants.

Limitations of this DNP project were that there was a small sample size, and participants did not attend every session due to issues with work, weather, doctors' appointments, traffic, transportation, and fatigue. One participant dropped out after the first session because she was not ready to cope with her MS yet in a group setting. Two other participants had

scooters/wheelchairs, so it was more difficult for them to get to sessions. They only made it to one session each, so their data was excluded from the study as well. One participant did not respond to the week 9 questionnaire, however her other information was still incorporated into the results. The support session was only offered on Wednesdays from 10-11:30.

### **Discussion**

The results from this DNP project do not show a statistically significant change in health-related quality of life after using peer support groups. The lack of statistical significance in the data could reflect that MS is an illness in which symptoms can vary on a daily basis, as well as the fact that participants did not attend every session. The lack of statistical significance could also relate to the small sample size, and the small amount of time spent in the support groups over only a 6-week period.

Peer support has been proven to be effective in many forms of chronic illness, and there are some other studies that also examine peer support in MS that have results that show improvement in health-related quality of life. Peer support can be used in various ways, and people respond to it differently. Overall, many participants in this DNP project reported using peer support, however they use it when they feel it necessary to help improve their lives. The forms of peer support that participants used in this DNP project included formal group meetings, informal group meetings, going to camp for people with MS, and using friends, family, and therapists to help them cope. Others do not use peer support, but do report that it is helpful to talk to others living with multiple sclerosis.

Being diagnosed with a chronic illness such as MS, that has the potential to progress over time with uncontrollable, worsening symptoms, can present complications for a patient, such as feelings of loss of control over life circumstances. To manage this disease, it is important to

tailor therapy around ensuring adequate quality of life. Peer support can help people cope with stress, and can allow them to form relationships with others who are going through similar situations. Ng, Amatya, & Khan (2013) received positive results from their peer support group for patients with MS that focused on behavior, coping strategies, and self-management techniques, and found that this did improve their HRQOL overall. Liu et al. (2015) used peer support in type 2 diabetes and this improved self-management and quality of life in this population of patients. On the other hand, Uccelli et al. found that peer support groups did not result in consistent improvement in QOL or depression in patients with MS.

It can be noted that not all people wish to take part in peer support groups (Peters, Somerset, Campbell & Sharp, 2003). One participant had never disclosed to anyone aside from his immediate family that he has MS, and he reported that he really enjoyed the DNP project sessions because it was nice to talk to others who could relate to what he had been through, and by doing this he may disclose his diagnosis to more people. Participants reported finding it useful to discuss ways to disclose MS to others.

With MS, younger patients typically do not have the progressive form of the disease, and therefore may have different symptoms than older patients who have MS (Peters, Somerset, Campbell & Sharp, 2003). It was noted that health-related quality of life was not consistent in a majority of participants, and this made sense when considering that symptoms can vary on a daily basis for people living with MS, so some days they may rate their quality of life higher than other days.

### **Suggestions and Future Recommendations**

This DNP Project may have had different results if more participants were recruited and if the peer support groups were longer sessions, over a longer period of time. Many MS peer

support groups meet monthly for at least 2 hours. The support groups also may be more helpful if they were divided into types of MS, such as a support group for people living with relapsing-remitting MS or a support group for people living with progressive MS. Further research should be done to determine what participants consider valuable information to discuss, and support groups can be tailored to improve more specific goals for participants. Quality of life is a broad concept, and means different things to different people. It is not an easy outcome to measure because quality of life can be influenced by many factors.

### **Conclusion**

Multiple sclerosis is a chronic illness that can affect physical ability, memory, cognition, and emotional function (Salminen, Kanelisto, & Karhula, 2014). This illness can go through periods of remission and periods of progression without any warning, which can cause fear and feelings of unknown in this population of patients (Wilkinson & das Nair, 2013). People living with MS may feel isolated due to their symptoms. It has been shown that peer support can be useful in many forms of chronic illness (Stanhope & Henwood, 2014). There have been some studies that have evaluated peer support in patients with MS, but many of the studies are outdated and do not focus on peer support between people with multiple sclerosis interacting with other people with multiple sclerosis. This project involved a DNP student living with MS, who led peer support groups for participants who have MS, and evaluated whether the peer support groups improved the participants' health-related quality of life. Questionnaires were done before the peer support groups began, and then at three, six, and nine weeks. The quality of life did not steadily improve in participants with the peer support groups, and did not show consistency in answering similarly worded questions, which could be due to a number of reasons. MS is an illness in which symptoms may wax and wane, and perceptions of quality of



life also may change with associated symptoms. In the future, it may be helpful to have peer support groups run over a longer period of time, with more frequent questionnaires, to evaluate quality of life in participants.

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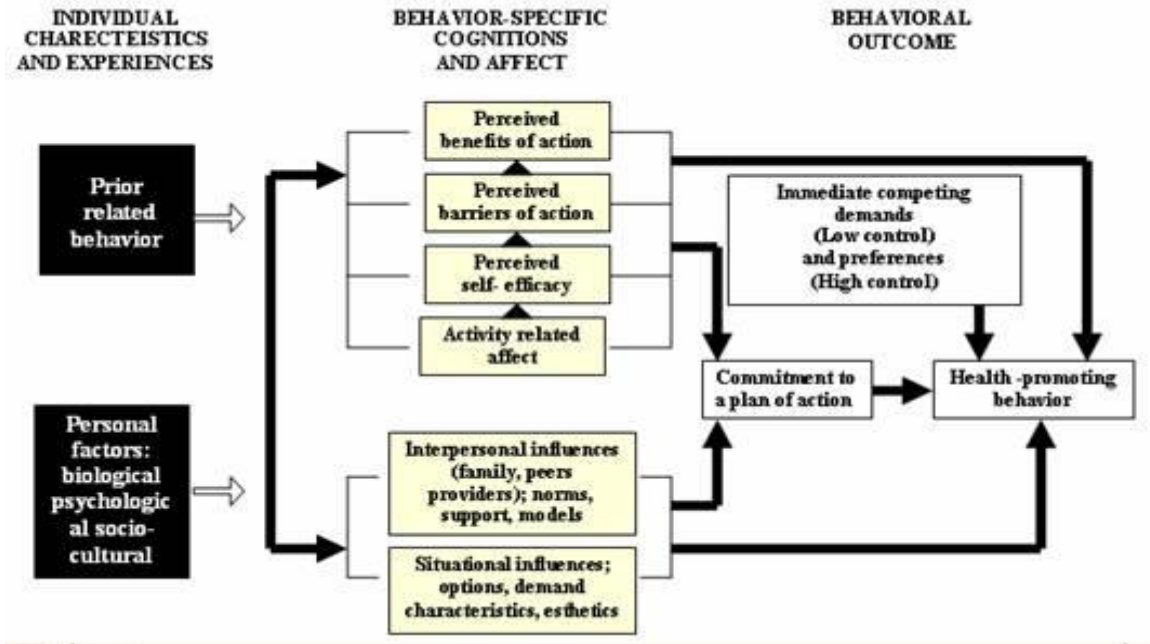
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## Appendix A

### Nola Pender's Health Promotion Model



(Gonzalo, 2011)

## Appendix B

### PDSA Cycle

- Plan
- obtain proposal approval

- create outline of topic ideas to discuss during the peer support groups to serve as a guide
- determine who the MS Nurse will be to provide support during peer support groups
- determine a population of participants for the support groups by sending emails via Linda Guidod's database
- Participants will sign consent forms

**Do**

- Participants will complete the pre-survey (see Appendix C)
- Peer support groups will begin
- Participants will complete questionnaires at 3, 6, and 12-week mark (see Appendix C) to evaluate health-related quality of life in the participants, and whether the peer support groups are beneficial.

**Study**

- Analyze data from the completed pre-surveys, as well as follow-up surveys at 3, 6, and 12-week marks
- Evaluate whether there is improvement in quality of life over the duration of the peer support groups
- Determine what changes need to be made

**Act**

- Modify current plan according to lessons learned until quality of life is improved

(Institute of Healthcare Improvement, 2016)

## **Appendix C**

### **Survey for Weeks 1, 3, 6, and 9**

1. What is your age?

18-24

25-34

35-44

45-54

55-64

65-74

75 or older

2. What is your gender?

3. Please describe your race/ethnicity.

4. How long have you been diagnosed with multiple sclerosis?

5. What types of symptoms do you have related to MS? (circle)

Fatigue

Issues with bladder

Issues with bowels

Cognitive impairment

Gait disturbance

Issues with vision

Spasticity

Numbness/tingling

Depression

Anxiety

Other: please describe:

6. Have you ever used peer support in the past? (circle)

Yes

No

7. Have you ever taken part in a peer support group? (circle)

Yes

No

Health Status: This asks about how you view your health status. Please circle the appropriate response.

8. MS affects my everyday life.

Strongly disagree

Disagree

Neutral

Agree

Strongly agree



9. In general, would you say your health is:

Poor

Fair

Good

Very Good

Excellent

How do you rate these in your life?:

10. I get sick easier than most people:

Definitely false

Mostly false

Not sure

Mostly true

Definitely true

11. I am as healthy as everyone I know

Definitely false

Mostly false

Not sure

Mostly true

Definitely true

12. I think my health is going to get worse

Definitely false

Mostly false

Not sure

Mostly true

Definitely true

13. How often does your physical/emotional health interfere with your social life?

Not at all

Slightly

Moderately

Quite a bit

Extremely

14. I get sick easier than other people

Definitely false

Mostly false

Not sure

Mostly true

Definitely true

15. I am as healthy as anybody I know

Definitely false  
Mostly false  
Not sure  
Mostly true  
Definitely true

16. I expect my health to get worse

Definitely false  
Mostly false  
Not sure  
Mostly true  
Definitely true

17. My health is excellent

Definitely false  
Mostly false  
Not sure  
Mostly true  
Definitely true

18. How often are you discouraged by your health problems?

Never  
A little  
Sometimes  
Good bit of time  
Most times  
Always

19. How often are you frustrated about your health?

Never  
A little  
Sometimes  
Good bit of time  
Most times  
Always

20. How often are you worried about your health?

Never  
A little  
Sometimes  
Good bit of time  
Most times  
Always

21. How often are you weighed down about your health condition?

Never

A little  
Sometimes  
Good bit of time  
Most times  
Always

22. What is your rating of your quality of life?

1  
2  
3  
4  
5  
6  
7  
8  
9  
10

23. How do you feel about your life as a whole?

Terrible  
Unhappy  
Mostly dissatisfied  
Mixed  
Mostly satisfied  
Pleased  
Delighted

24. This illness has caused my friendships/relationships to change:

For the worse  
Not at all  
For the better

25. I have someone who will help me if I need it:

A little  
Sometimes  
Most times  
Always

(National Multiple Sclerosis Society, 2016).

## **Appendix D**

### Scoring System

1. What is your age?

18-24

55-64

65-74

2. What is your gender?

Male = 1

Female = 0

3. Please describe your race/ethnicity.

4. How long have you been diagnosed with multiple sclerosis?

Scoring: # of years diagnosed = that score

5. What types of symptoms do you have related to MS? (circle)

Fatigue

Issues with bladder

Issues with bowels

Cognitive impairment

Gait disturbance

Issues with vision

Spasticity

Numbness/tingling

Depression

Anxiety

Other: please describe:

Scoring: 1 point per symptom reported

6. Have you ever used peer support in the past? (circle)

Yes = 1

No = 0

7. Have you ever taken part in a peer support group? (circle)

Yes = 1

No = 0

If used formal support setting: 1 point

If used in informal group setting: 1 point

If used peer/friendships: 1 point

Health Status: This asks about how you view your health status. Please circle the appropriate response.

8. MS affects my everyday life.

Strongly disagree = 2

Disagree = 1

Neutral = 0

Agree = -1

Strongly agree = -2

9. In general, would you say your health is:

Poor = -1

Fair = 0

Good = 1

Very good = 2

Excellent = 3

How do you rate these in your life?:

10. I get sick easier than most people:

Definitely true = -2

Mostly true = -1

Not sure = 0

Mostly false = 1

Definitely false = 2

11. I am as healthy as everyone I know

Definitely true = 2

Mostly true = 1

Not sure = 0

Mostly false = -1

Definitely false = -2

12. I think my health is going to get worse

Definitely true = -2

Mostly true = -1

Not sure = 0

Mostly false = 1

Definitely false = 2

13. How often does your physical/emotional health interfere with your social life?

All the time = -2

Quite a bit = -1

Moderately = 0

Slightly = 1

Not at all = 2

14. I get sick easier than other people

Definitely true = -2

Mostly true = -1

Not sure = 0  
Mostly false = 1  
Definitely false = 2

15. I am as healthy as anybody I know  
Definitely true = 2  
Mostly true = 1  
Not sure = 0  
Mostly false = -1  
Definitely false = -2

16. I expect my health to get worse  
Definitely true = -2  
Mostly true = -1  
Not sure = 0  
Mostly false = 1  
Definitely false = 2

17. My health is excellent  
Definitely true = 2  
Mostly true = 1  
Not sure = 0  
Mostly false = -1  
Definitely false = -2

18. How often are you discouraged by your health problems?  
Always = -3  
Most times = -2  
Good bit of the time = -1  
Sometimes = 0  
A little = 1  
Never = 2

19. How often are you frustrated about your health?  
Always = -3  
Most times = -2  
Good bit of the time = -1  
Sometimes = 0  
A little = 1  
Never = 2

20. How often are you worried about your health?  
Always = -3  
Most times = -2  
Good bit of the time = -1  
Sometimes = 0

A little = 1  
Never = 2

21. How often are you weighed down about your health condition?

Always = -3  
Most times = -2  
Good bit of the time = -1  
Sometimes = 0  
A little = 1  
Never = 2

22. What is your rating of your quality of life?

1 = 1  
2 = 2  
3 = 3  
4 = 4  
5 = 5  
6 = 6  
7 = 7  
8 = 8  
9 = 9  
10 = 10

23. How do you feel about your life as a whole?

Mixed = 0  
Mostly satisfied = 1  
Pleased = 2  
Delighted = 3

24. This illness has caused my friendships/relationships to change:

For the worse = -1  
Not at all = 0  
For the better = 1

25. I have someone who will help me if I need it:

A little = 1  
Sometimes = 2  
Most times = 3  
Always = 4

(National Multiple Sclerosis Society, 2016).

## **Appendix E**

### Participant Demographics

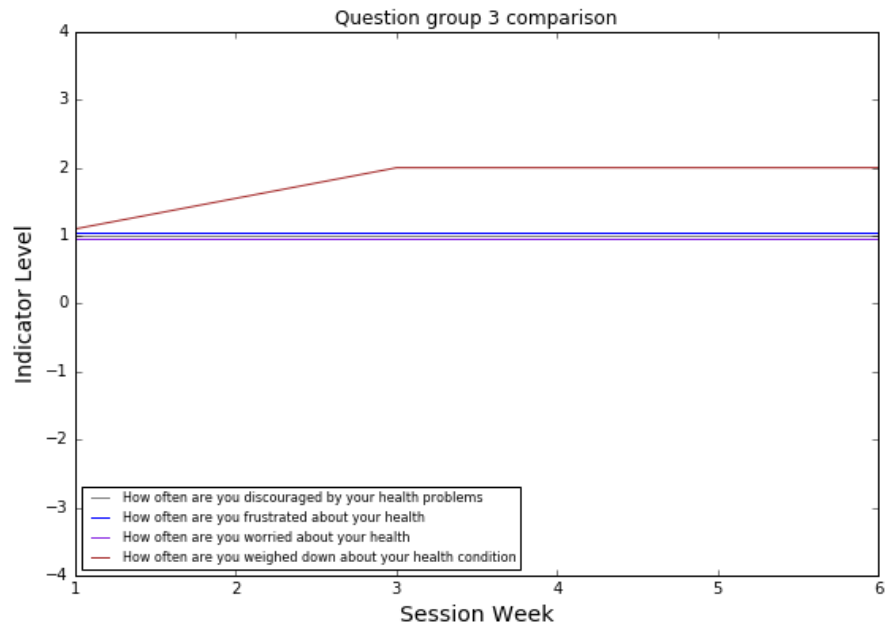
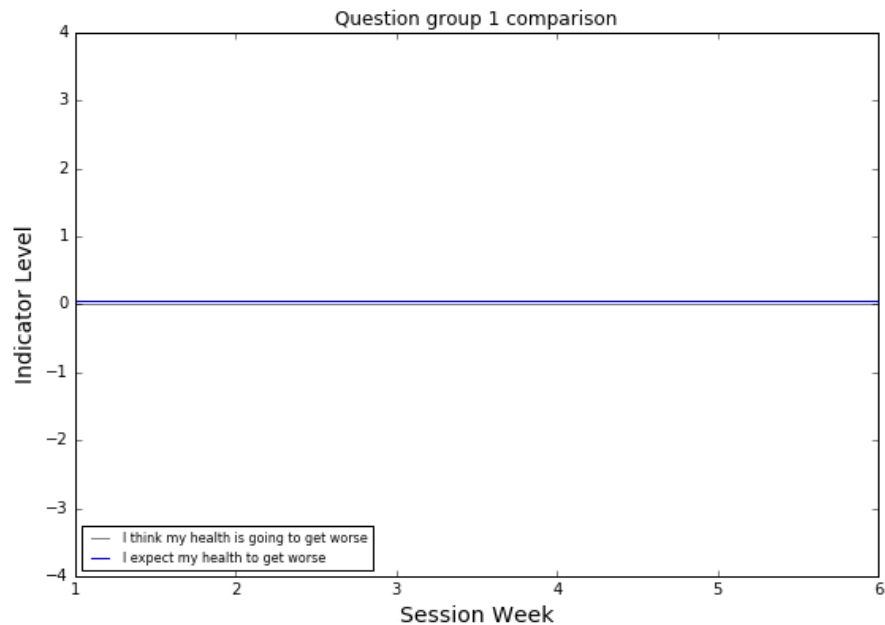
<b>Code</b>	<b>Gender</b>	<b>Age (years old)</b>	<b>Duration of MS (in years)</b>	<b>Ethnicity</b>
1	Male	55-64	10	Caucasian
2	Male	55-64	32	Caucasian
3	Female	55-64	40	Caucasian
4	Male	55-64	22	Caucasian
5	Male	65-74	12	Caucasian
6	Female	65-74	21	Caucasian
7	Female	18-24	8	Caucasian



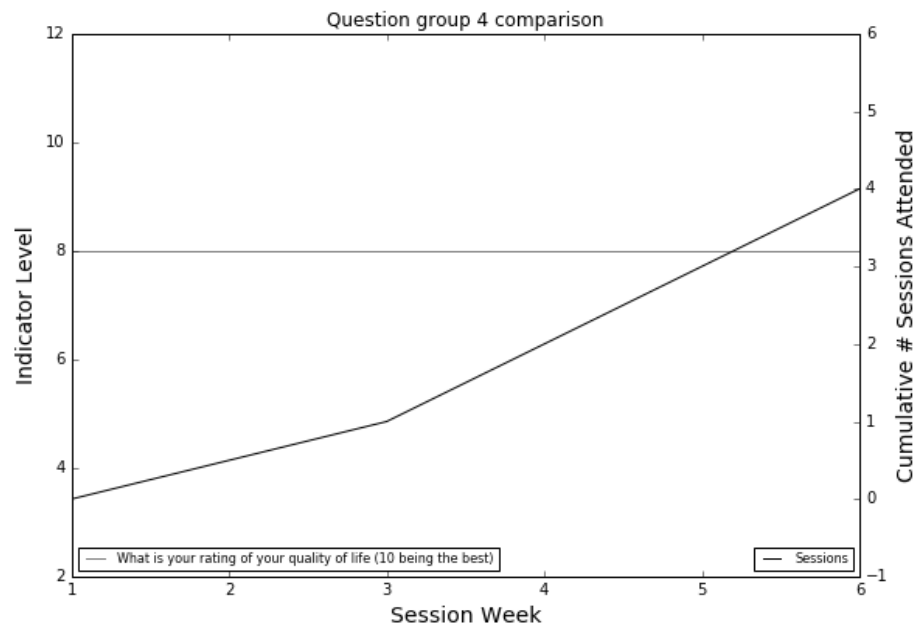
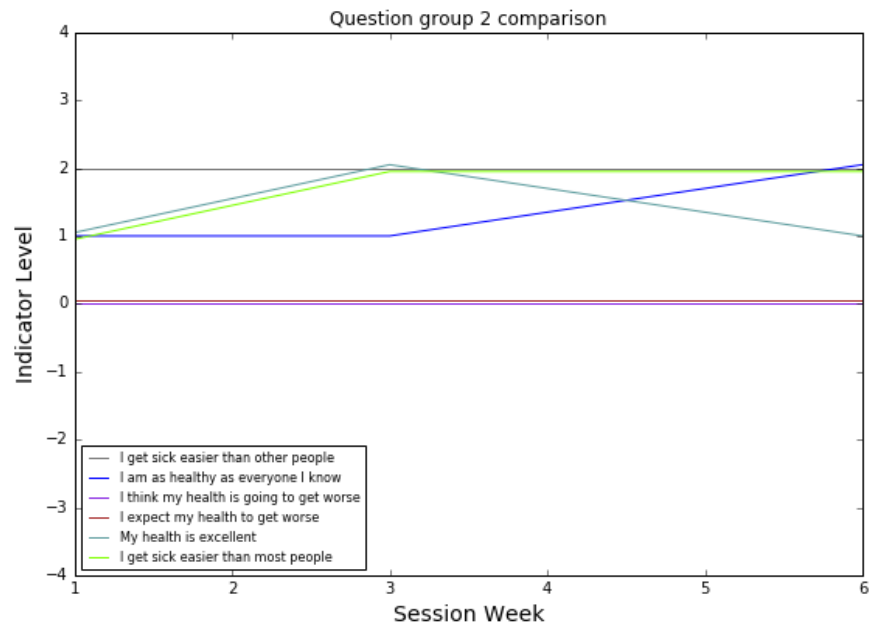
## Appendix F

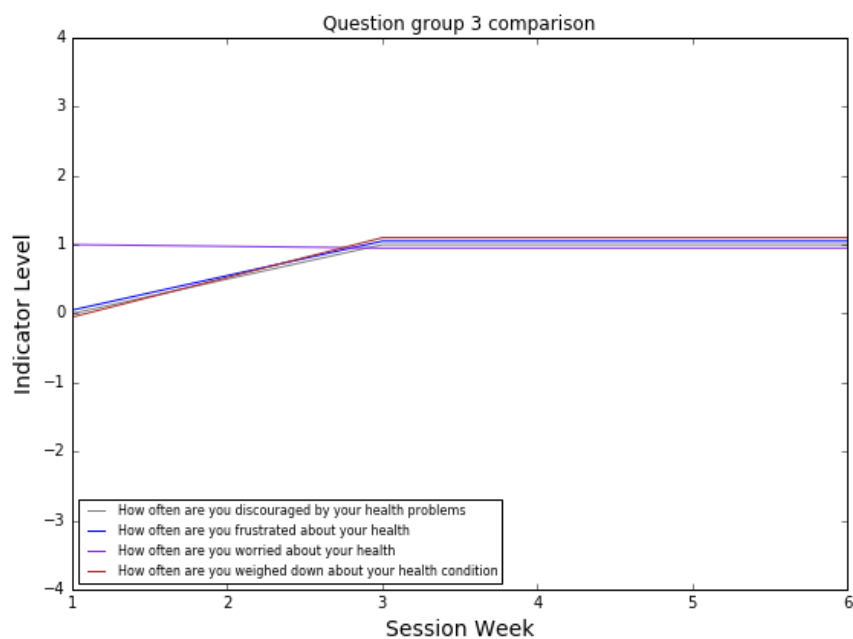
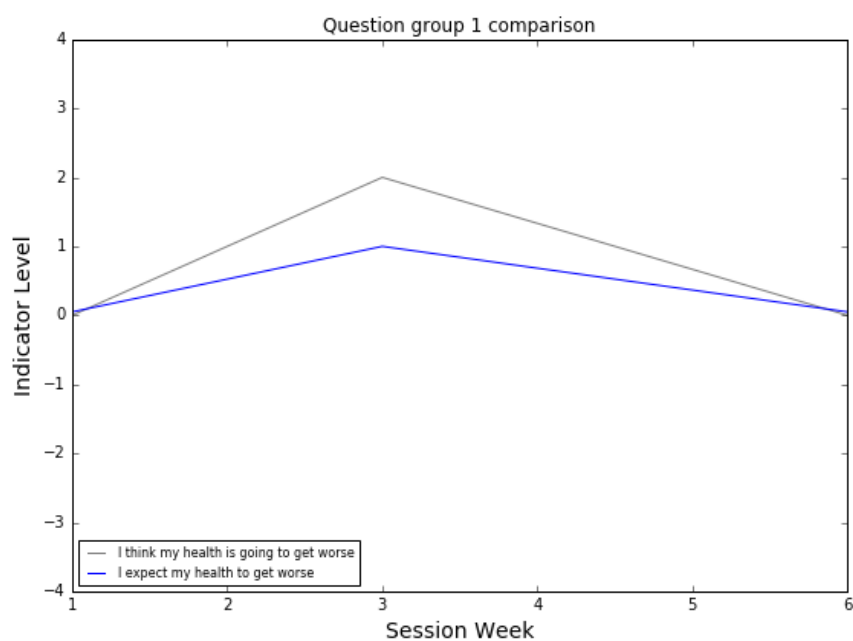
### Consistencies Per Participant on Category Questions

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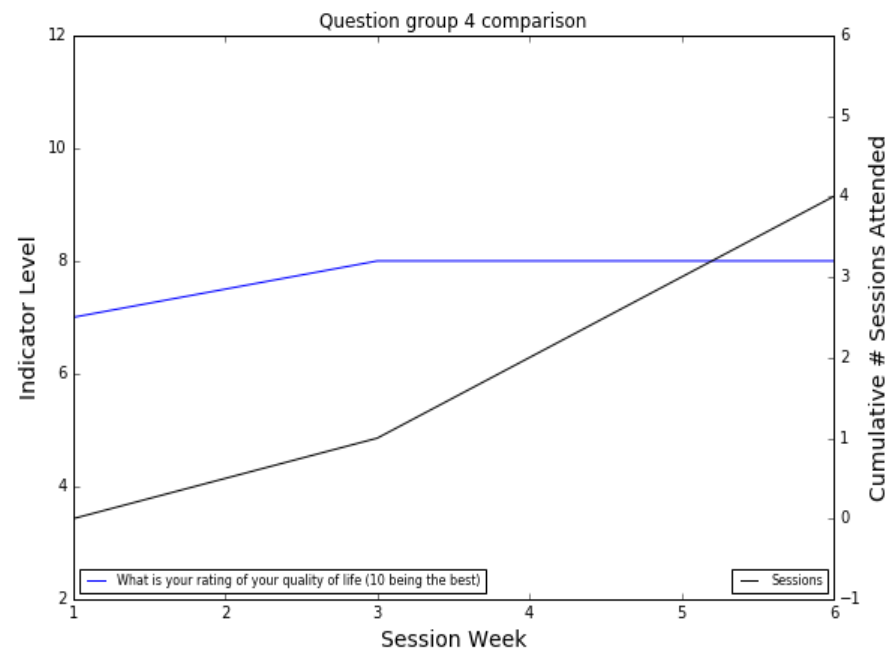
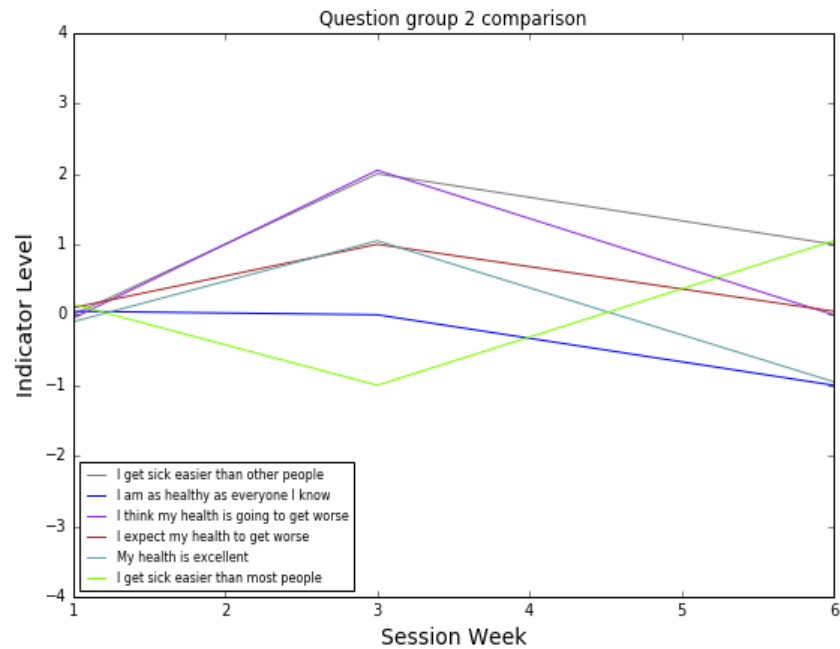


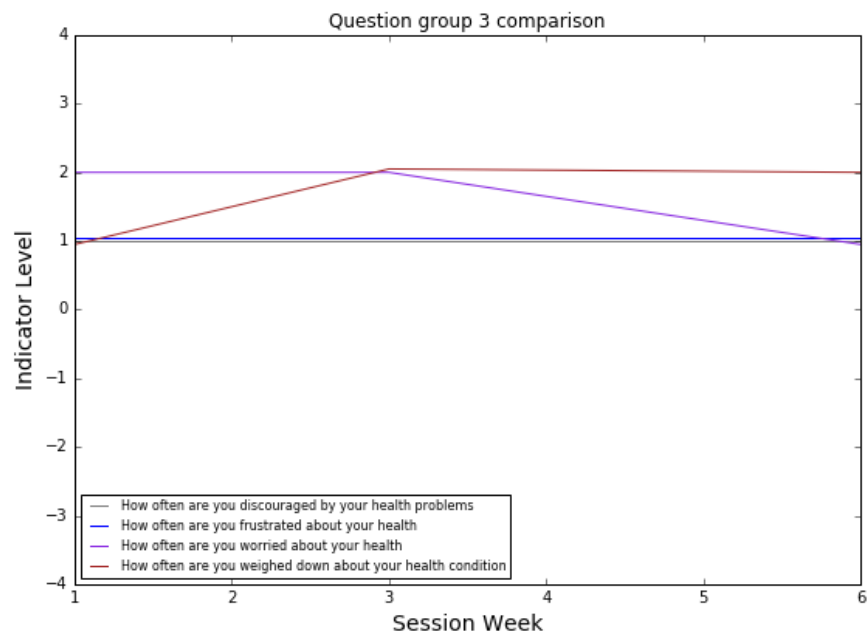
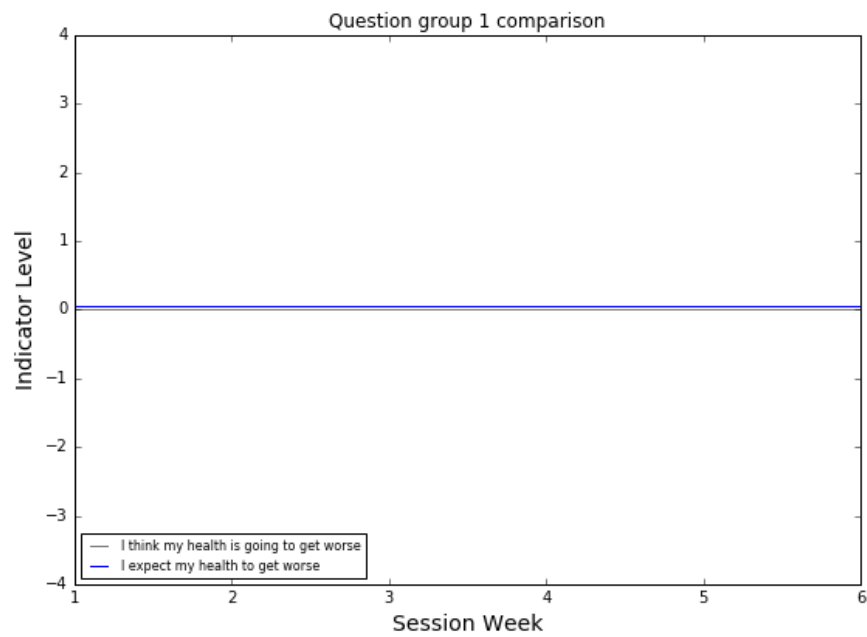
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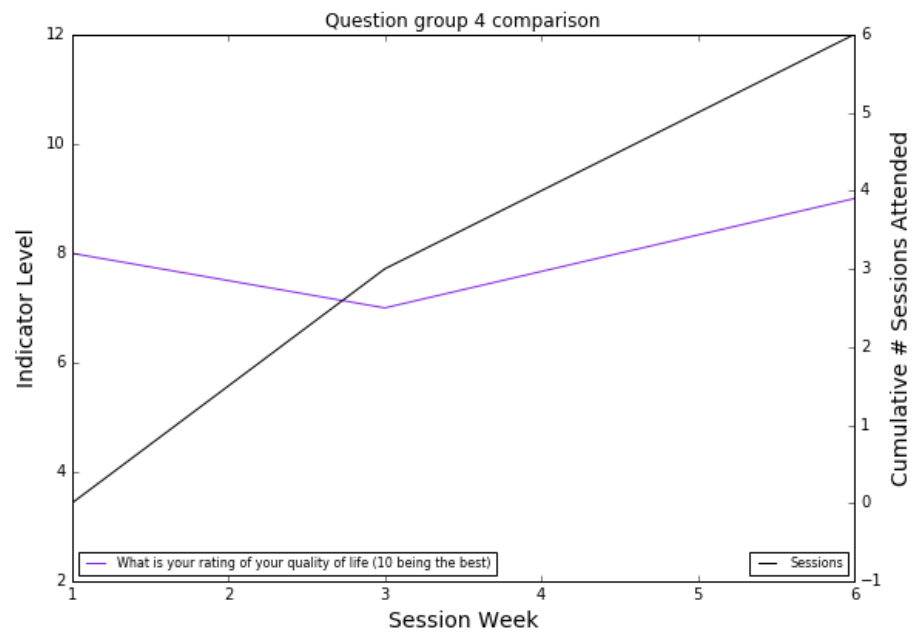
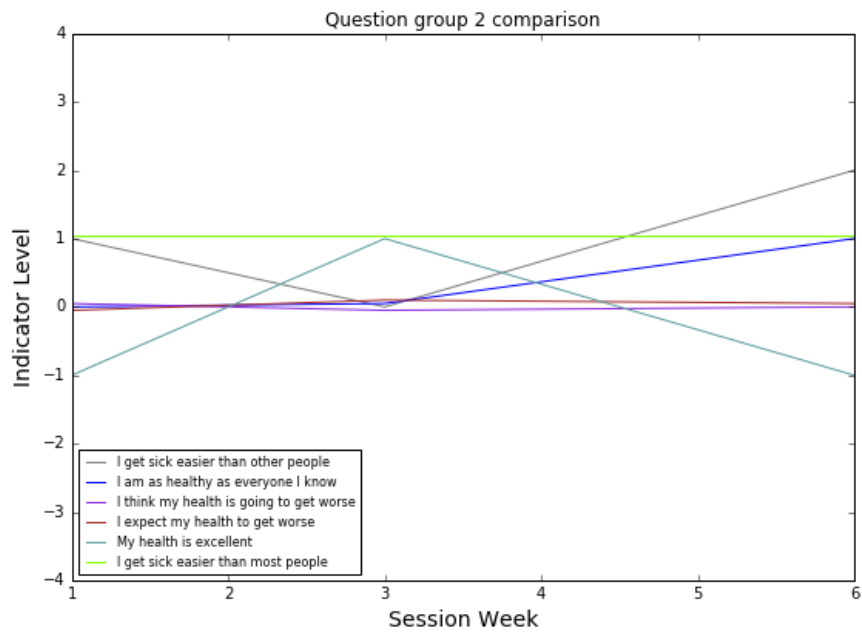
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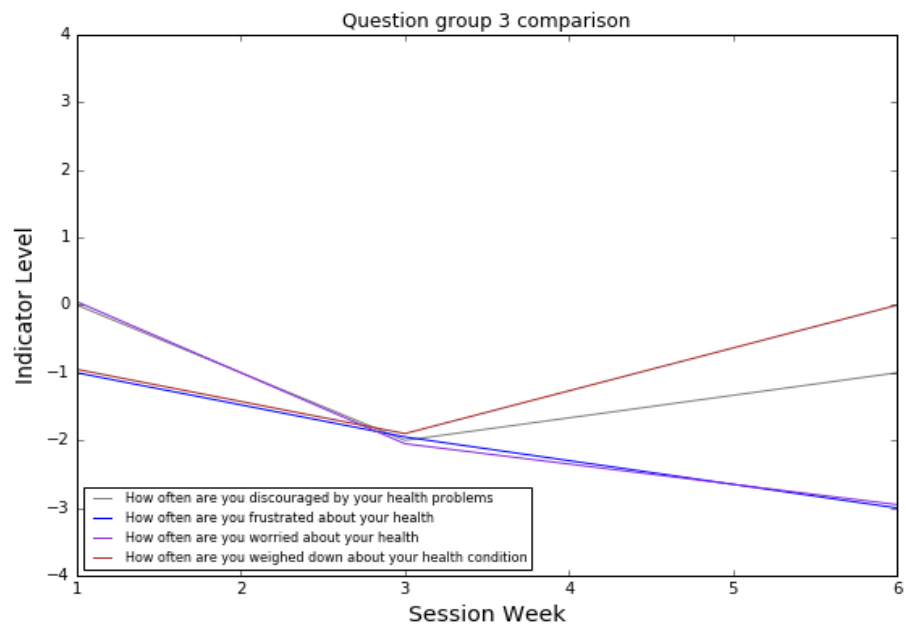
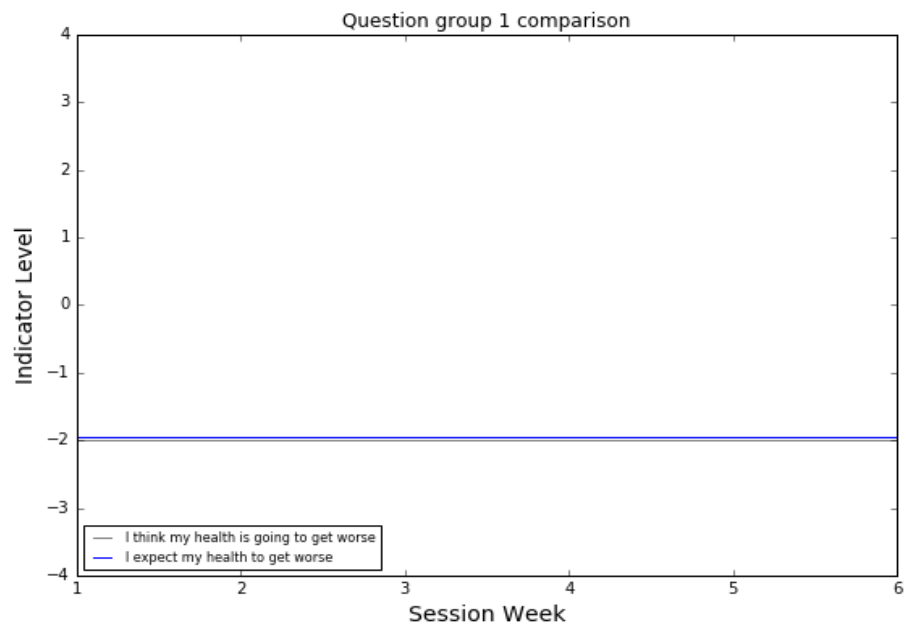
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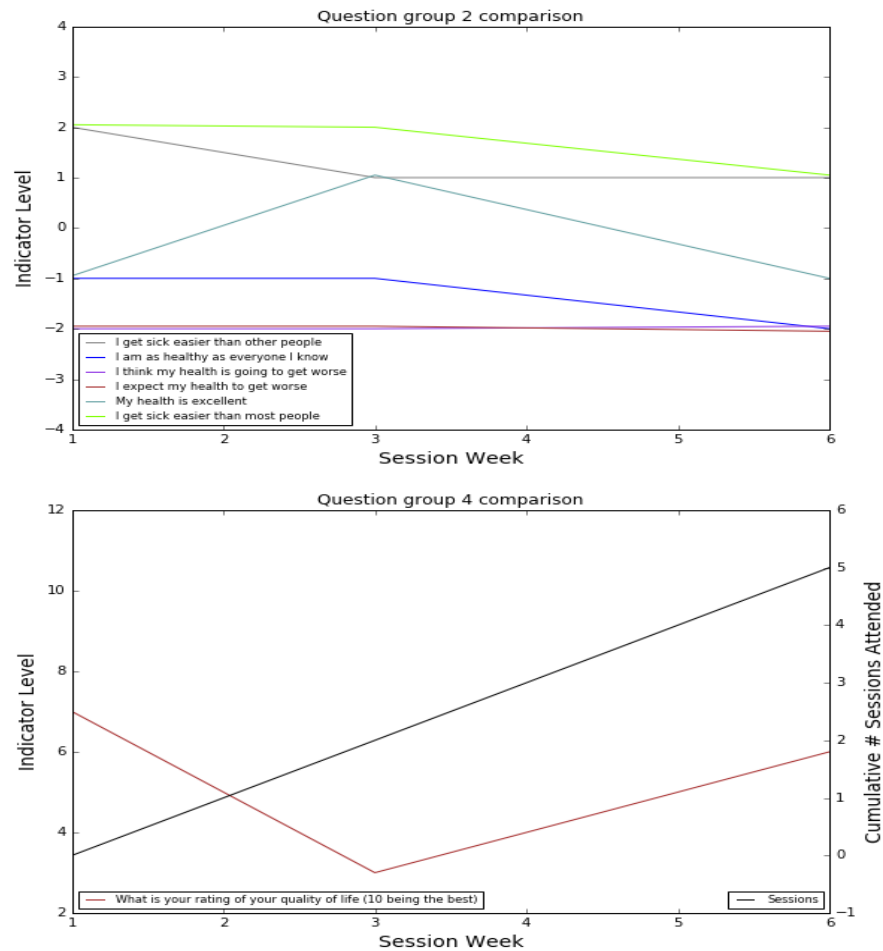
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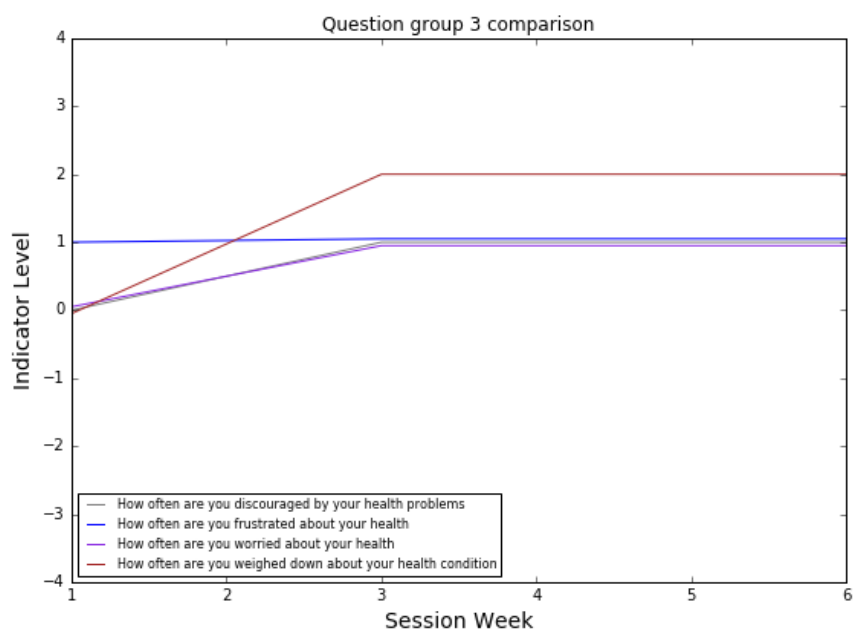
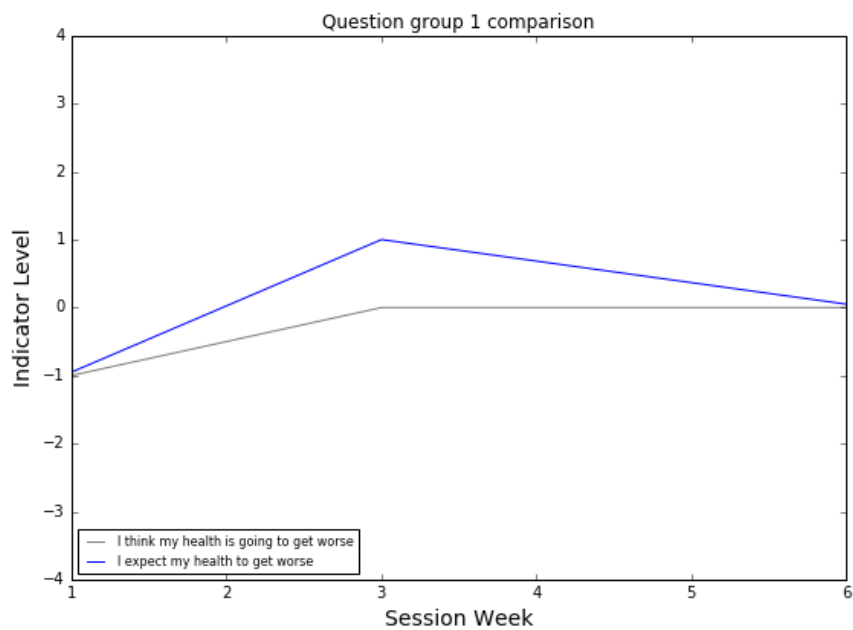


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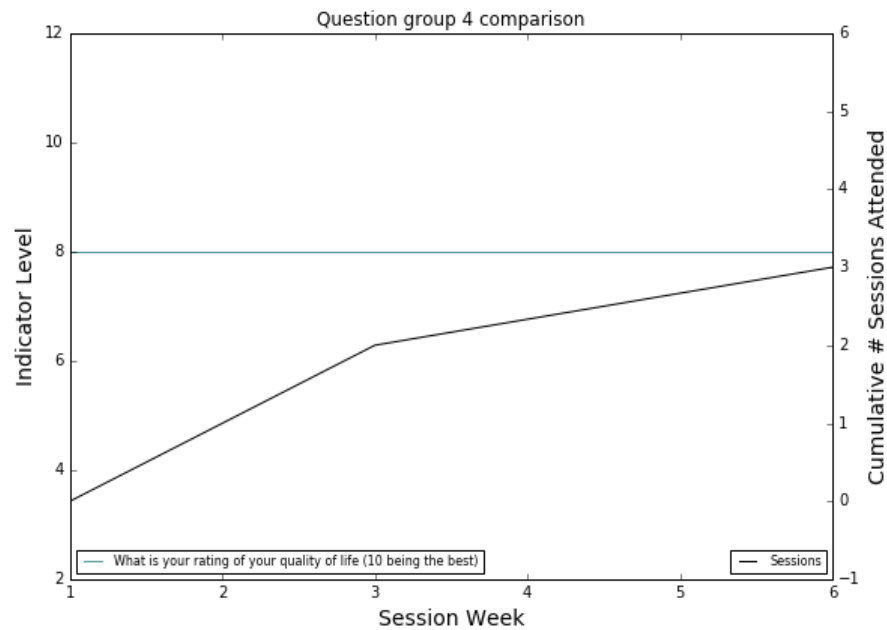
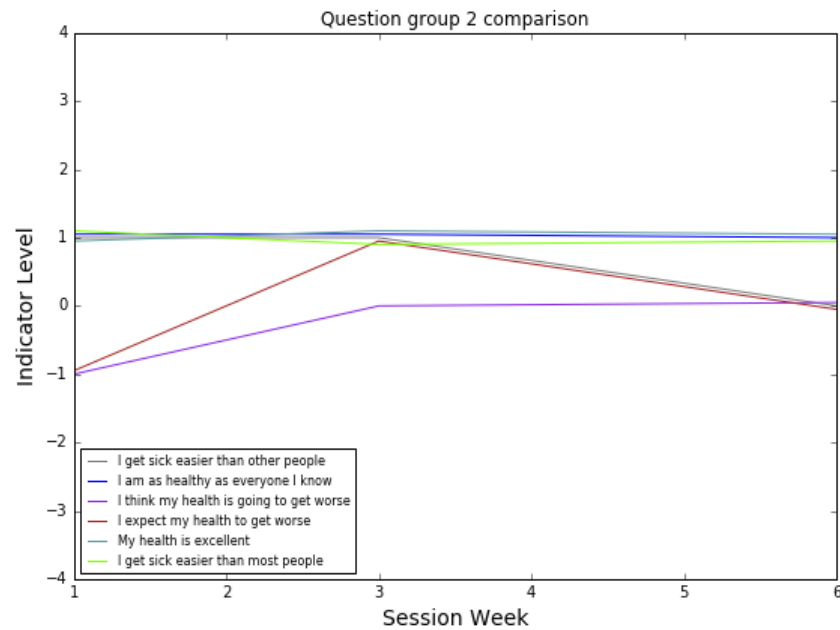
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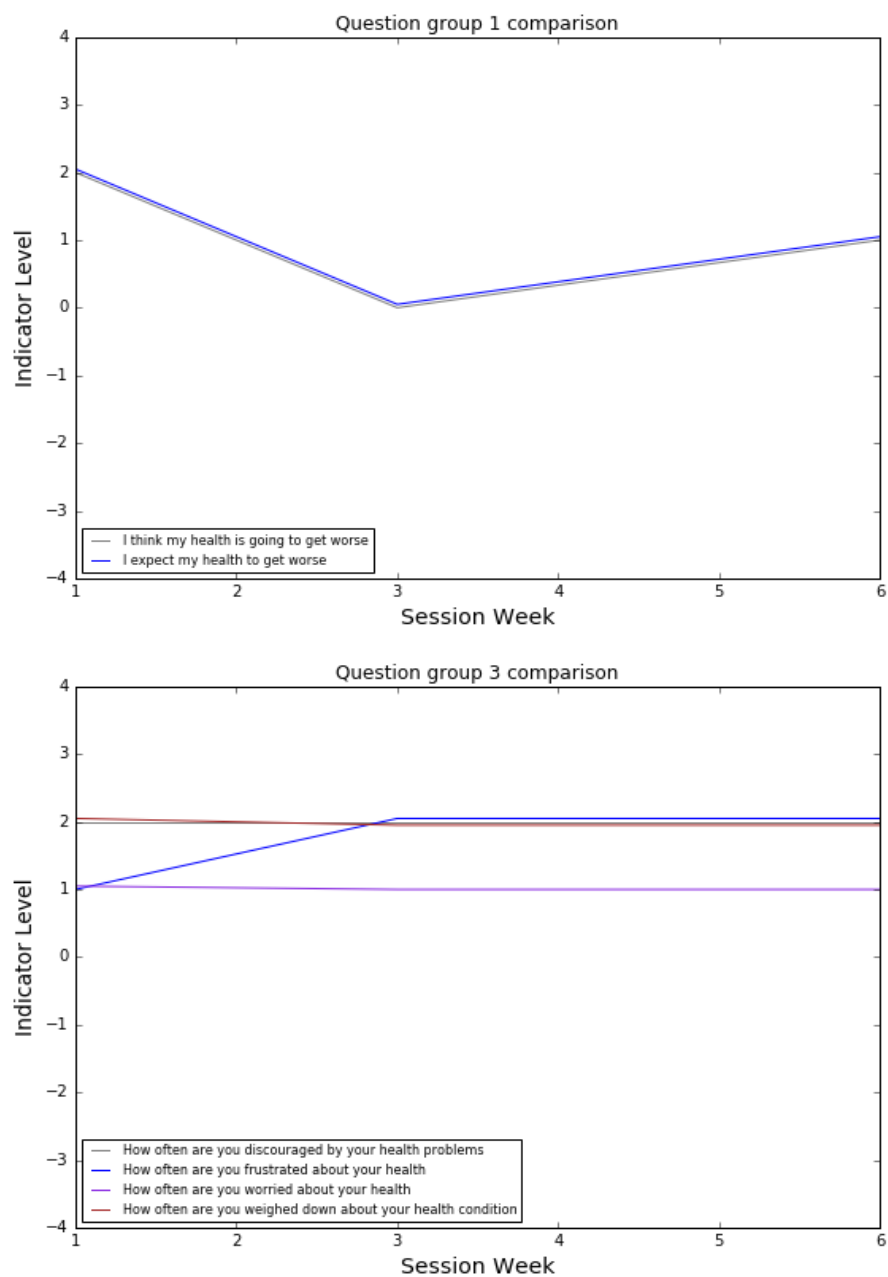




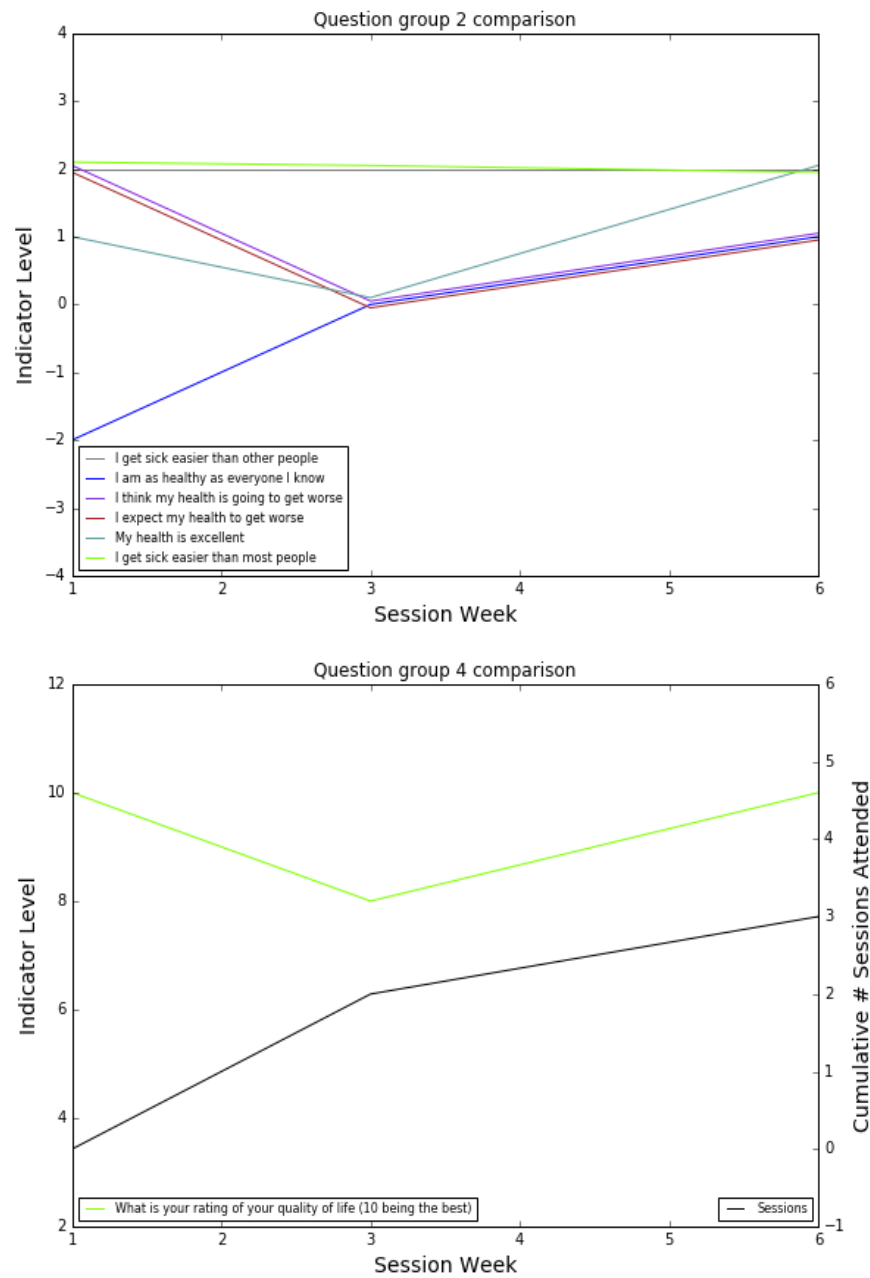
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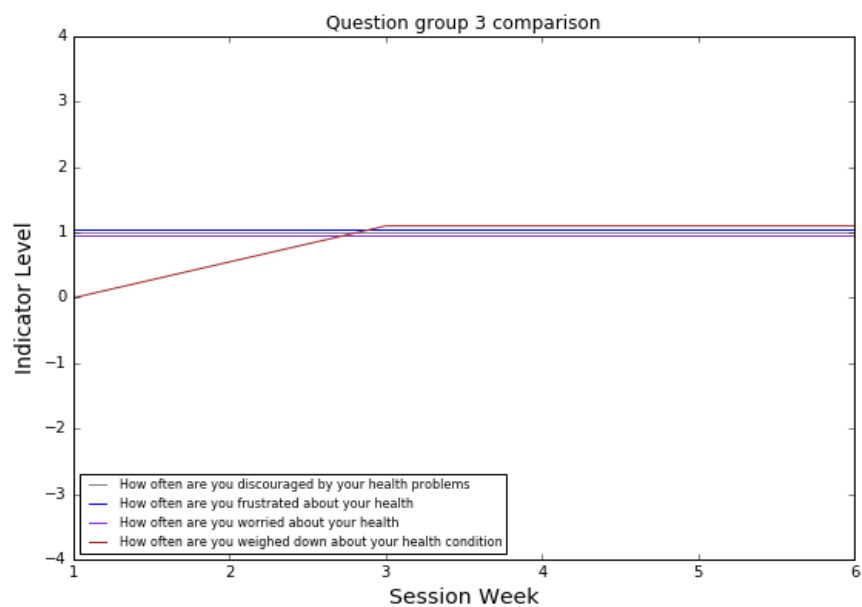
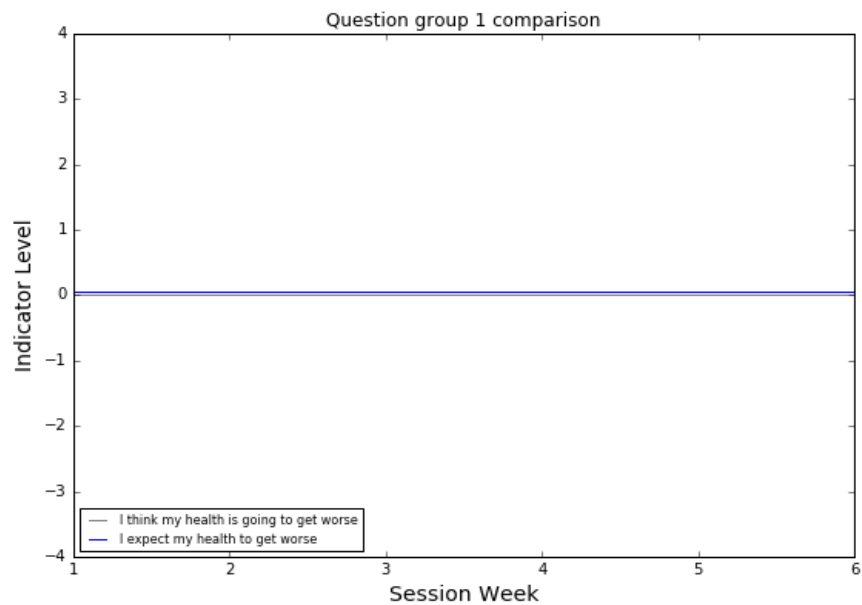
### Person 5 Consistency of Reporting on Similar Questions by Session Week (Continued)



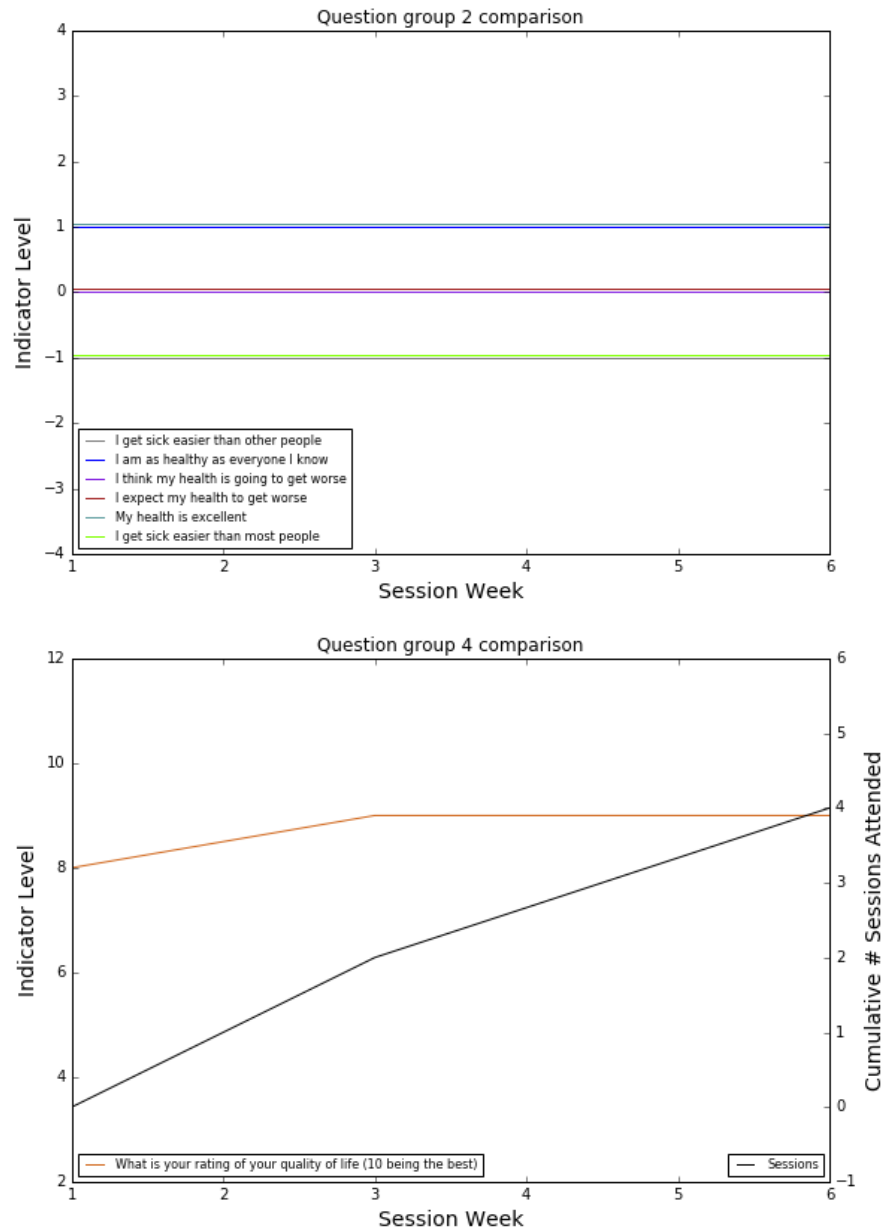
**Person 6 Consistency of Reporting on Similar Questions by Session Week**

### Person 6 Consistency of Reporting on Similar Questions by Session Week (Continued)



**Person 7 Consistency of Reporting on Similar Questions by Session Week**

### Person 7 Consistency of Reporting on Similar Questions by Session Week (Continued)



**Quality of Life Indicator Change by Session Week**